

Michael Wasley



A CEO passionate about supporting Victorian families

As CEO of Very Special Kids, a Malvern-based organisation which supports families with a child living with a life limiting condition, Michael Wasley is extremely passionate about supporting Victorian families who need it most.

“Most of the children we support will not reach adulthood. Although, with increases in clinical technology, life expectancy is improving. We care

for children with life-threatening conditions by providing a children’s hospice and professional family support services. We look after approximately 850 families across Victoria with ongoing support from diagnosis all the way through to bereavement and beyond,” Mr Wasley said.

Michael has been CEO of Very Special Kids for more than five years. He comes from genU (previously Karingal), a large not-for-profit provider of disability services throughout Victoria.

“In doing all the background research I could prior to being appointed to the role of CEO, I completely underestimated how positive Very Special Kids is for an organisation that exists for very sad reasons,” he said.

“A lot of the time, families are seeking support with their circumstances in life. Our support assists families in being able to maintain employment, looking after their other kids in addition to caring for their child living with a life limiting condition 24/7.

“Even if the child has died, we continue to support families and help them cope with the ongoing challenges of bereavement and grief, and to look forward and focus on their future. Families are incredibly grateful for the support so most of our engagements are mainly positive and the work is, of course, incredibly humbling and fulfilling.

“I’ve met so many amazing families over the years. The most memorable moments are when you see children live past their 18th birthday, beyond their expected life capacity, and they are no longer receiving our services because they’re still alive,” he said.

Very Special Kids built Australia's first children's hospice and is currently Victoria's only children's hospice. The team is in the process of demolishing and rebuilding the facility.

"One thing that resonated with me a couple of years ago was when a 17-year-old, who was staying with us at the time for respite, wanted to play Grand Theft Auto because it's something he'd normally do at home.

"We didn't have the space for him to do that privately at the time, so he was using the main television in the main lounge area and of course he thought it was very funny to turn the sound up while staff kept trying to turn the sound down.

"It made me think. If this is what he normally does at home, then why can't he do that here? If he comes to respite to give his family a break then we should be doing everything we can to make his stay enjoyable, and he can do the things he wants to do and not be in an environment where he doesn't feel comfortable," he said.

Mr Wasley said he has learnt so much about palliative care over the last five years. He said holistic palliative care is a very important and underrated discipline of health in Australia.

"I've learnt that the approach in Australian health towards palliative care is quite low compared to other Western countries, partly because it deals with imminent death, which a lot of people, including people who work in health, don't want to face. Australia also has a more medical approach rather than a holistic approach to palliative care.

"Palliative care support doesn't necessarily mean you have to give up on that person's life or tell the family that you are giving up on that child or person's life, but you're just trying to cover all your bases and make sure that the family and their child or the person is getting the best possible care, whichever path their health takes – that's really important and that's what Palliative Care Victoria is there to do," Mr Wasley said.

"With so many competing demands and the complicated health system we have in Australia, it's very easy to lose sight of the importance of palliative care if it's not continually raised."

"Working in palliative care is much more important than most people anticipate. It has enormous and measurable benefits. It really helps society at the most critical time. It's a job where you never question if you're making a difference – you always know your role is having a big impact. It's an absolute privilege to be working with families at such a difficult time in their lives," he said.